

The Patient Concerns Inventory integrated as part of routine head and neck cancer follow-up consultations: frequency, case-mix, and items initiated by the patient

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ABSTRACT

INTRODUCTION The National Institute for Health and Care Excellence guidance *Improving Supportive and Palliative Care for Adults with Cancer* (2004) and the *Cancer Reform Strategy* (2007) support the premise that assessment and discussion of patients' needs for physical, social, psychological, and spiritual wellbeing should be undertaken during oncology follow-up. We report the use of the Patient Concerns Inventory in a routine head and neck cancer clinic setting over a seven-year period, summarising the number of available clinics, the number of patients completing the inventory within a clinic, the range of clinical characteristics and the concerns they wanted to discuss.

METHODS The data were analysed from oncology follow-up clinics between 1 August 2007 and 10 December 2014. Audit approval was given by the Clinical Audit Department, University Hospital Aintree.

RESULTS There were 386 patients with 1198 inventories completed at 220 clinics, median 6 (range 4–7) per clinic. The most common concerns raised by patients across all the clinic consultations were dry mouth (34%), fear of recurrence (33%), sore mouth (26%), dental health (25%), chewing (22%) and fatigue/tiredness (21%).

CONCLUSIONS The incorporation of the Patient Concerns Inventory as part of routine oncology clinics allows for a more patient initiated and focused consultation available to the majority of patients throughout their follow-up. The inventory allows for greater opportunity to provide holistic targeted multiprofessional intervention and support.

KEYWORDS

Patient Concerns Inventory – Holistic needs assessment – Patient reported outcomes – Health-related quality of life – Oral cancer

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Introduction

Patient-reported outcomes measures (PROMS) have an established place in research and surgical practice in national programmes such as for patients undergoing hip replacement, knee replacement, varicose vein and groin hernia surgery,^{1,2} and evaluation of care pathways such as orthopaedic enhanced recovery after surgery.³ For many years, patient-reported outcomes have been used in head and neck cancer and have focused on health-related quality of life (HRQOL).⁴ These findings have helped to improve the quality of information concerning patient-reported outcomes; for example 'what will I be like',⁵ and to inform treatment protocols.⁶ There is a body of literature around the difficulties that patients with head and neck cancer experience in relation to a range of functions such as speech,

swallowing, appearance, chewing and dry mouth. Dysfunction in these functional aspects is associated with negative impact of mood and anxiety. They also have a detrimental influence on social integration and the carers/family dynamic.⁴

In addition to HRQOL assessment, cancer units are encouraged to assess and discuss the patient's physical, social, psychological and spiritual wellbeing as part of oncology follow-up.^{7,8} The use of holistic assessments facilitates a more patient-centred approach on an individual basis. One method of assessment which encourages patients to raise issues in consultations that they might otherwise be reluctant to discuss is the Patient Concerns Inventory (PCI) for the head and neck (PCI-HN).⁹ The basis of this approach stems from the use of question prompt lists.¹⁰ This approach has been adapted as a holistic item prompt list and as a tool

to uncover unmet needs in a cancer outpatient clinic. It can be used in conjunction with, and to complement HRQOL outcomes.¹¹

Although the use of PROMs in routine cancer clinical practice is growing, there are a number of barriers to implementation.¹² Surgeons might be reluctant to embrace PROMs for conceptual, methodological and practical reasons.¹³ There is a burden involved in data collection. It is challenging to collect and incorporate these data efficiently into clinical care and to integrate this approach into a busy outpatient setting. The aim of this study was report the use of the PCI-HN in a routine head and neck cancer clinic setting over a seven-year period, summarising the number of available clinics, the number of patients completing the inventory within a clinic, the range of clinical characteristics and the concerns they wanted to discuss.

Methods

The study sample comprised the patients with oral and oropharyngeal cancer of one consultant (SNR) attending outpatient clinics from 1 August 2007 to 10 December 2014, who completed the PCI-HN directly on to a computerised system on the Aintree-Hospital secure server. Patients included were disease free and under routine follow-up at least six weeks after completing treatment. Patients were excluded if they were pretreatment, palliative, attending clinic for other postoperative wound management or if they were part of an outcomes study in clinic. The intention was to allow patients to complete the PCI-HN while waiting in clinic for each of their planned routine outpatient consultations. When approached in the routine clinic setting, virtually all patients participated. PCI-HN data were obtained from patients immediately before attending their routine follow-up clinic. The data were collected as part of routine practice meeting the local clinical governance department criteria for service evaluation. This study was approved by the Clinical Audit Department and did not require formal submission to an ethics committee.

Development of the PCI-HN has been described elsewhere and is the subject of several papers.^{9–11} It is a holistic, self-reported 56-item prompt list that allows patients to select issues for discussion in their consultations (Fig 1). The exact number of items has varied slightly over time, with subsequent revisions adding to the list. The PCI-HN also includes a list of 18 professionals listed alphabetically. Patients are asked to indicate items from the prompt list about which they are concerned and want to discuss with the doctor during their consultation. In addition, patients are asked to indicate which professionals from the list they would like to speak with or be referred to.

At Aintree Hospital, the PCI-HN is usually administered together with a head and neck specific cancer HRQOL questionnaire,¹⁴ the University of Washington Quality of Life version 4 (UWQOL).¹⁵ The UWQOL consists of 12 domains, scaled from 0 (worst) to 100 (best) according to the hierarchy of response. For this study, the UWQOL was analysed in various ways, including its single six-point 'overall' quality of life measure for which patients are asked to consider

Head and Neck

Patient Concerns Inventory [PCI]

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Study Number: _____

Date: _____

PCI

Please choose from the list of those issues you would specifically like to talk about in your consultation in clinic today. You can choose more than one option (tick boxes).

Physical and functional well-being: <input type="checkbox"/> Activity <input type="checkbox"/> Appetite <input type="checkbox"/> Bowel habit <input type="checkbox"/> Breathing <input type="checkbox"/> Chewing/eating <input type="checkbox"/> Coughing <input type="checkbox"/> Dental health/teeth <input type="checkbox"/> Dry mouth <input type="checkbox"/> Energy levels <input type="checkbox"/> Fatigue/tiredness <input type="checkbox"/> Hearing <input type="checkbox"/> Indigestion <input type="checkbox"/> Mobility <input type="checkbox"/> Mouth opening <input type="checkbox"/> Mucus <input type="checkbox"/> Nausea <input type="checkbox"/> Pain in the head and neck <input type="checkbox"/> Pain elsewhere <input type="checkbox"/> Regurgitation <input type="checkbox"/> Salivation <input type="checkbox"/> Shoulder <input type="checkbox"/> Sleeping <input type="checkbox"/> Smell	<input type="checkbox"/> Sore mouth <input type="checkbox"/> Swallowing <input type="checkbox"/> Swelling <input type="checkbox"/> Taste <input type="checkbox"/> Vomiting/sickness <input type="checkbox"/> Weight Treatment related: <input type="checkbox"/> Cancer treatment <input type="checkbox"/> Regret about treatment <input type="checkbox"/> PEG tube <input type="checkbox"/> Wound healing Social care and social well-being: <input type="checkbox"/> Carer <input type="checkbox"/> Dependents/children <input type="checkbox"/> Financial benefits <input type="checkbox"/> Home care/District nurse <input type="checkbox"/> Lifestyle issues (smoking/alcohol) <input type="checkbox"/> Recreation <input type="checkbox"/> Relationships <input type="checkbox"/> Speech/voice/being understood <input type="checkbox"/> Support for my family	Psychological, emotional and spiritual well-being: <input type="checkbox"/> Appearance <input type="checkbox"/> Angry <input type="checkbox"/> Anxiety <input type="checkbox"/> Coping <input type="checkbox"/> Depression <input type="checkbox"/> Fear of the cancer coming back <input type="checkbox"/> Fear of adverse events <input type="checkbox"/> Intimacy <input type="checkbox"/> Memory <input type="checkbox"/> Mood <input type="checkbox"/> Self-esteem <input type="checkbox"/> Sexuality <input type="checkbox"/> Spiritual/religious aspects <input type="checkbox"/> Personality and temperament Others (please state):
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Figure 1 Head and Neck Patient Concerns Inventory

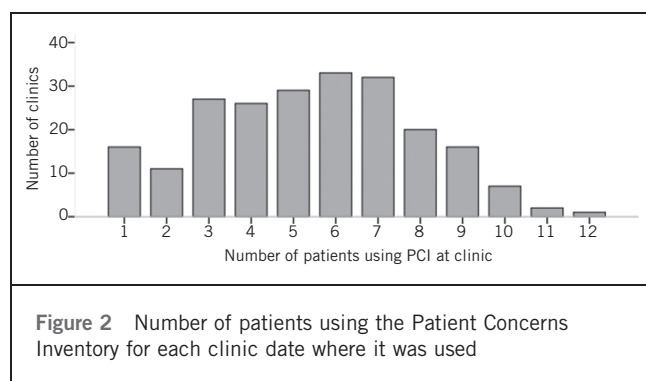
not only physical and mental health but also other factors such as family, friends, spirituality or personal leisure activities important to their enjoyment of life. Previous work has helped to facilitate the use of the UWQOL into routine clinical practice by defining a 'significant problem' on each UWQOL domain, as derived from domain scores and from the relative importance of domains during the previous week.¹⁶

The PCI-HN and UWQOL are available as a software application to allow self-administration using a standard touch-screen computer. The physician used a print-out of the responses in real time during the consultation.

Results

From 1 August 2007 to 10 December 2014, the inventory was completed 1198 times by 386 patients at 220 clinics of one consultant (SNR), median 6 (range 4–7) per clinic (Fig 2). The frequency of use of PCI-HN by clinic date is shown in Figure 3. Apart from technical issues at the beginning of 2012, the use of the inventory was maintained at similar levels (median six per clinic to October 2011 and median five per clinic from July 2012).

Median age of patients at first clinic was 63 years (range 55–71 years, $n = 385$) and time to first clinic where PCI was



used was 10 months (5–31 months, $n = 337$). Table 1 describes the clinical characteristics of the patients who used the PCI-HN during the seven-year period and indicates the wide range of applicability. Figure 4 shows the wide range of issues and concerns that patients select before their consultation that they want to discuss during their consultation. The most common concerns raised by the patients across all the clinic consultations were dry mouth (34%), fear of recurrence (33%), sore mouth (26%), dental health (25%), chewing (22%) and fatigue/tiredness (21%). Figure 5 indicates the health professionals who patients want to speak with or be referred on to.

Discussion

With advances in information technology in the NHS, it is possible to include patient-reported outcomes in clinical care frequently and routinely. A condition-specific item prompt list used in the outpatient consultation helps to elicit patient concerns and allows discussion of issues that otherwise could be missed. This can improve the clinician–patient communication and symptom management, as well as allowing the opportunity for multiprofessional support. The routine use of the PCI-HN is being evaluated in a randomised control trial and the primary outcomes at one year are significant and meaningful difference in quality of life, socioemotional dysfunction and distress.¹⁷

This the first time that the availability and use of PCI in clinics has been tracked over time. The data are only from one clinic setting so caution needs to be applied when extrapolating these finding across other areas; however, it does confirm that this approach is feasible. This is a consecutive series collated over many years and reflects current practice of outpatient review. The number of patients completing the PCI in clinic (Figure 1) is indicative of the case mix, as patients are not included if they have been seen more recently than six weeks; for example those attending for wound dressings, first postoperative discharge, non-cancer (reconstructive cases), those who have recurrence of cancer or are palliative. Although there are only a few patients who refuse to complete the PCI, these too are added to the exclusion and are not flagged up for completion of the PCI when they attend clinic. There are other PCI modules under development and it might be that future palliative patients are identified and invited to complete a palliative-specific PCI. The PCI complements the consultation so sometimes it is quicker to see a patient without completing the PCI first if there is a backlog of patients waiting to use the computer. Although the PCI is available at the majority of clinics, Figure 2 shows that there was a block of time in late 2011 to early 2012 when the computer system was being upgraded and the new system piloted. It was unfortunate that the old system could not run concurrently with the new. Also, the availability of the PCI is occasionally compromised if the outpatient department's wi-fi fails. It is possible to use a paper version in these circumstances but as such failure is infrequent this option is deemed unnecessary. The other main reason for not being able to use the PCI in clinic is when the volunteer is on holiday. Since the system moved to an iPad a few years ago, it has been found that around three-quarters are willing to complete the inventory in the waiting room without the support of a volunteer.¹⁸ This makes its routine use more achievable as only one-quarter need to use a spare room alongside the clinic with a volunteer in attendance. The patients most likely to ask for support to complete the PCI are the elderly. In the future, it is hoped that the PCI will be available on a cloud via the internet and could be completed at home before attending clinic.

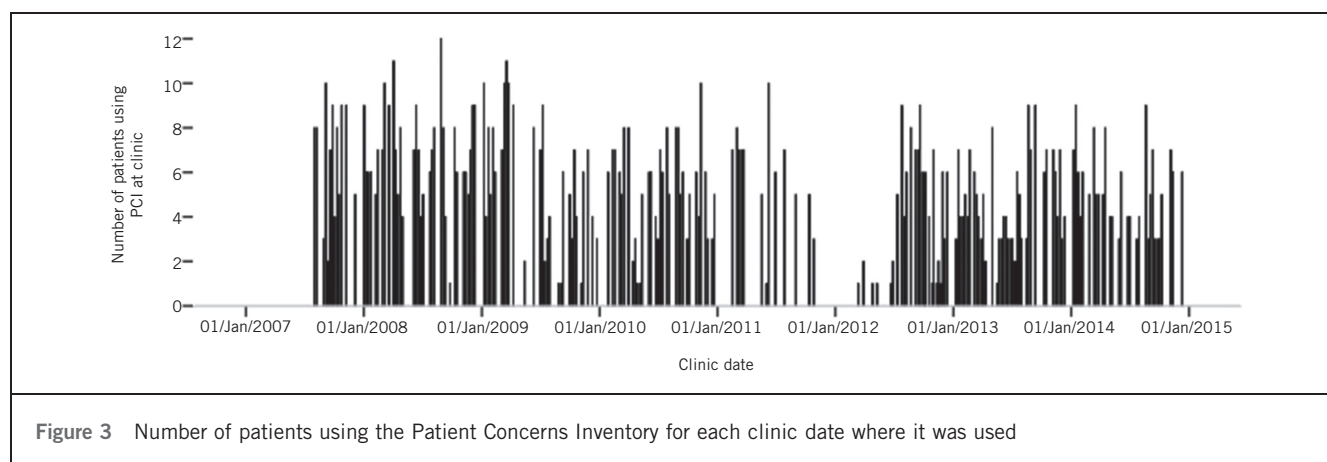
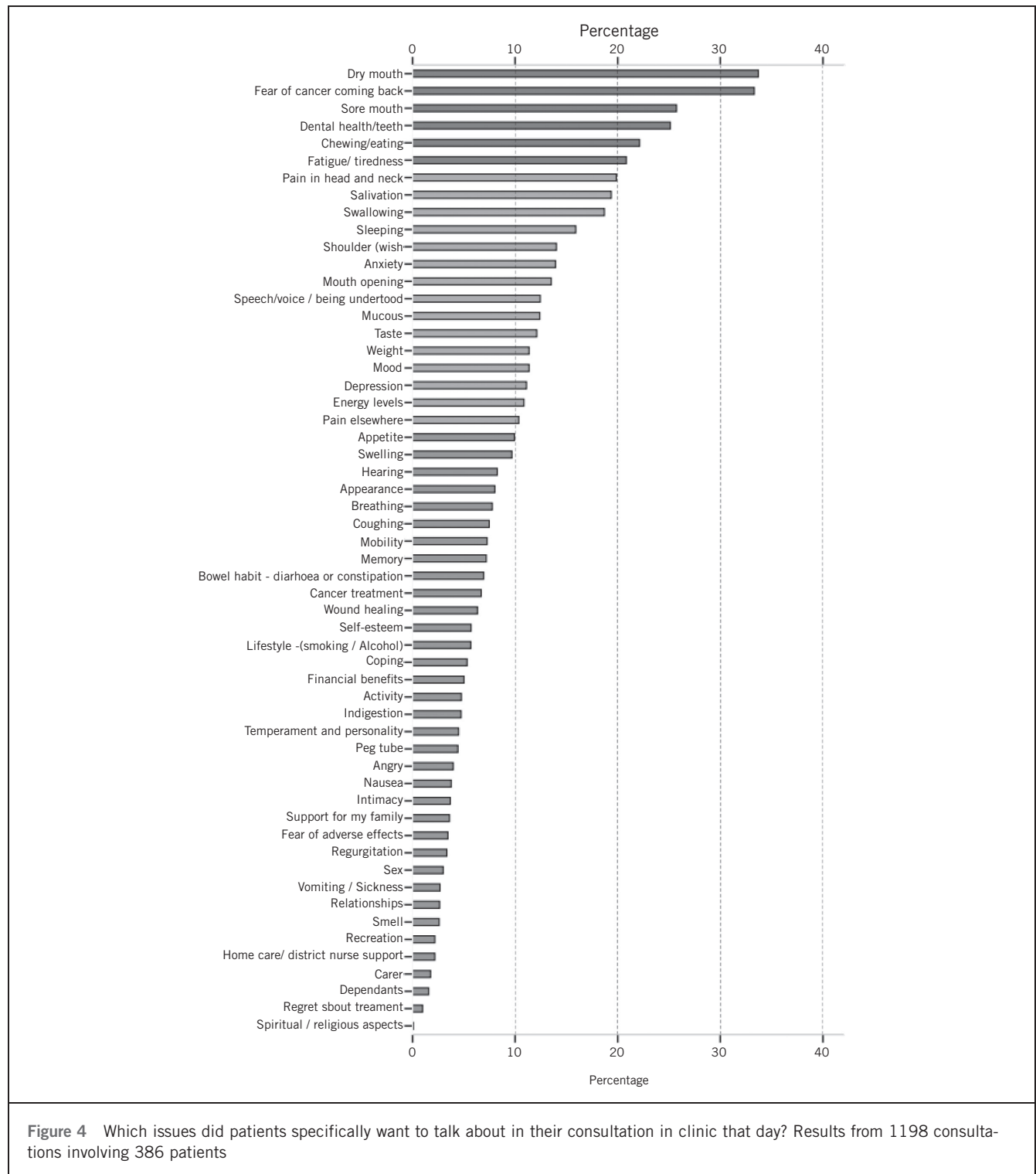


Table 1 Patient and clinical characteristics of the 386 patients who used the Patient Concerns Inventory before consultation with one consultant (SNR) between 1 August 2007 and 10 December 2014.

Characteristic	Patients	
	(%)	(n)
<i>Patient-based results (n = 386):</i>		
Gender:		
Male	58	225
Female	42	161
Primary treatment:		
Surgery alone	49	190
Surgery and adjuvant RT/CRT	37	142
RT/CRT, no surgery	9	34
Not known	5	20
Flap type, if surgery (known for 317/332):		
No flap	51	161
Soft	38	120
Composite	11	36
Overall clinical stage; known for 338/386:		
1	36	122
2	28	94
3	10	34
4	26	88
Diagnosis (known for 373/386):		
Squamous cell carcinoma	83	311
Non-squamous cell carcinoma	17	62
Tumour site (known for 374/386):		
Oral:		
Buccal mucosa excluding retromolar	7	25
Retromolar areas	6	21
Tongue	26	99
Floor of mouth	19	70
Other oral	14	51
Oropharynx:		
Base of tongue	4	15
Tonsil	7	28
Soft palate	6	22
Other oropharynx	2	9
Others	9	34

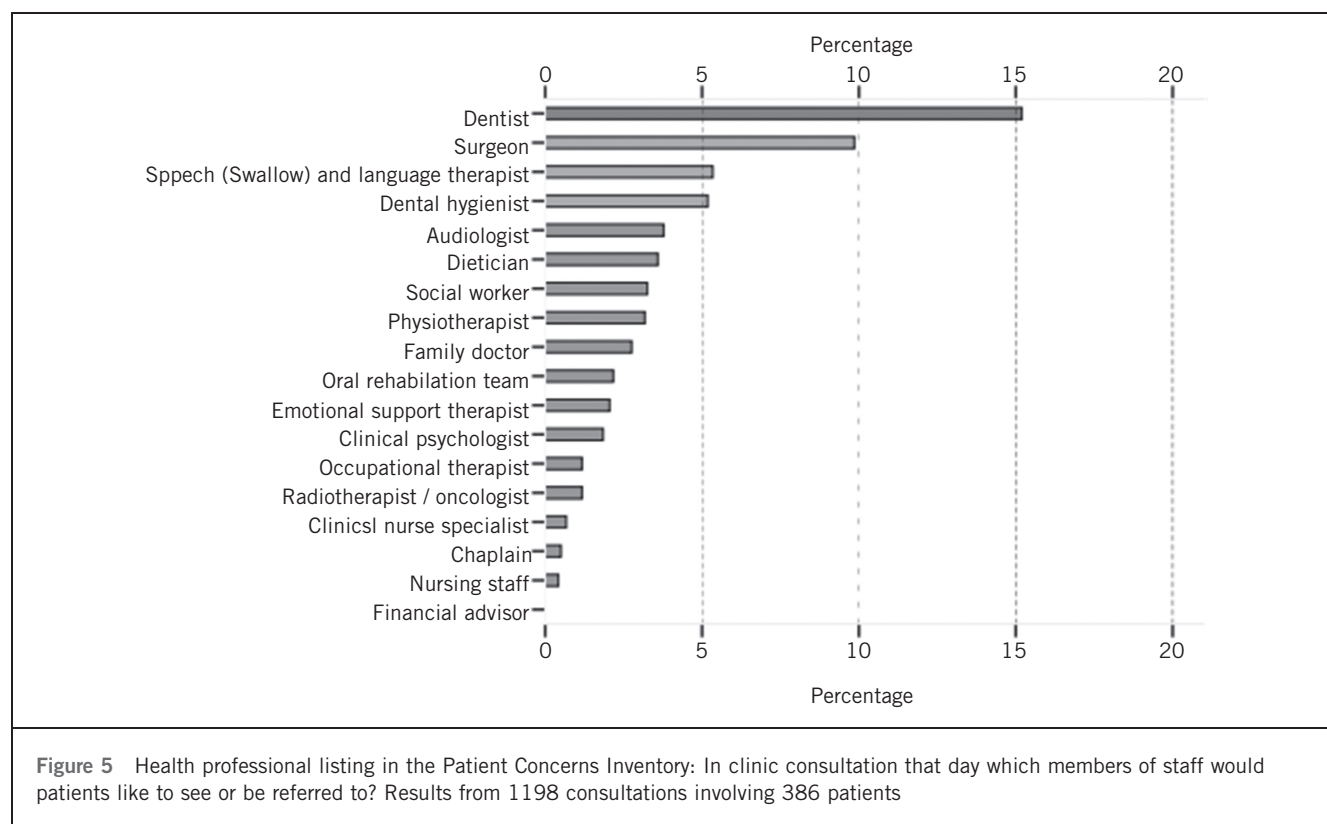
Characteristic	Patients	
Clinic-based results UWQOL (N = 1198):		
Overall QoL; known for 1184/1198		
Very poor	2	23
Poor	6	71
Fair	20	235
Good	34	403
Very good	32	377
Outstanding	6	75
‘Significant’ problem (known for 1190/1198)	24	283
Saliva		
Pain	20	236
Anxiety	20	233
Swallowing	18	211
Mood	17	198
Chewing	15	173
Taste	13	153
Shoulder	10	122
Speech	9	112
Activity	9	111
Appearance	9	107
Recreation	8	98
RT/CRT, radiation therapy/chemoradiation therapy; UWQOL, University of Washington Quality of Life Questionnaire.		

As shown in Figure 3, the main issues that patients wish to talk about in their consultation are dry mouth, fear of recurrence, sore mouth, dental health and fatigue. These are common adverse effects of treatment and the consultants, specialty trainees and appropriate members of the multiprofessional team have to be skilled at talking through these issues and signposting patients to suitable sources of information. There are some items on the PCI that come up very infrequently, such as regret about treatment. It is important to keep these items on the prompt list as, when they are identified by the patient, it is very important to address them. Content takes priority over psychometric properties. The current PCI has 56 items and in spite of that number, patients find it quick and easy to complete so there is no imperative to reduce the number of items or to remove infrequently highlighted issues. The most frequent items on the PCI are linked to health-related quality of life as measured by 'significant' problems in the UWQOL (Table 1). Difficulties with saliva, pain, anxiety, swallowing, mood and chewing might all be expected adverse effects but, for some



patients, their severity is such that where possible additional support through the members of the multiprofessional team is essential. The importance of dental aspect in this group is reflected in Figure 4 by the proportion wishing to see or be

referred to a dentist. The dentist has key roles in the overall wellbeing of the patient through maintaining dental health, supporting oral rehabilitation, assessing for a dental hygienist, assisting in surveillance of a recurrence or second



primary and reassurance. For some patients, it is difficult to find a general dental practitioner on the NHS who is willing to help meet their sometimes complex needs.

More clinical research is required to better understand the role of an item prompt list, such as the PCI, has on doctor-patient communication, time efficiency in clinics and holistic needs assessment with multiprofessional integration. Advances in information technology across the NHS using web-based patient-driven PROM collection processes have huge potential.¹⁹ These can help to address the acute and long-term physical and psychosocial comorbidities associated with treatments more effectively and redefine models of follow-up care.²⁰

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